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#### ABSTRACT

In 1986, Congress enacted Public Law 99-457, which outlined requirements for statewide early intervention systems and preschool services to assist young children who are either developmentally delayed or who have certain conditions which carry with them a high probability of resulting in developmental delay. Now known as the Individuals with Disabilities Education Act (IDEA), the law includes the following two programs that specifically target young children, birth through 5 years of age, with special needs: (1) the Program for Infants and Toddlers with Disabilities (previously Part H); and (2) the Preschool Grants Program (Part B, Section 619). This paper describes these two programs and discusses research findings about the effectiveness of early intervention for children with special needs. A table outlining some of the services provided under IDEA is included. Two case examples are given to illustrate the types of services that might be included in an early intervention program. The document also includes references and contact information for the National Information Center for Children and Youth with Disabilities (NICHCY). (SG)



### HEALTH SERVICES FOR YOUNG CHILDREN UNDER IDEA

### PROVIDING EARLY SERVICES TO CHILDREN WITH SPECIAL NEEDS & THEIR FAMILIES

PAPER NO. 1

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# **Health Services for** Young Children Under IDEA

Paper No. 1, May 1994

### Providing Early Services to Children With Special Needs and Their Families

Many children are born every year who would benefit from early intervention services. Advances in medical technology during the last 30 years have increased the survival rates of infants born prematurely or with disabling conditions. Other children will exhibit developmental delays during the preschool years.

At the same time, our understanding of and ability to provide the wide range of services needed by infants, toddlers, and young children with disabilities and their families has grown. More than ever, we are challenged to provide this wide range of services at the time when maximum benefit can be derived from them. All medical, health, education, and social service professionals working with these young children and their families have an important role in facilitating access to early intervention and preschool services.

### Why Is It Important to Identify and **Treat Delays Early?**

Research shows that growth and development is most rapid in the preschool years. Learning begins at birth and involves a constant interaction between the child and the environment. A child with developmental delay may be more limited in his or her ability to interact with the environment than a typically developing child and may not acquire many basic skills. The sooner problems or potential risk are identified, the greater the chance of eliminating or minimizing existing problems or preventing future problems.

Recent studies confirm the effectiveness of early intervention programs. The Infant Health and Development Program (Ramey et al., 1992), a national multi-site study, found that low-birthweight, premature infants who received comprehensive early intervention and preschool services scored

#### James

James was born prematurely weighing 2 pounds. Although he has no life-threatening medical problems, he still is hospitalized in the NICU at 3 months of age. His mother, Tina, is a single, teenage mother who receives limited financial and emotional support from her family. In fact, there is a history of abuse in her family. Tina is living with other relatives but is not happy with this arrangement. Tina has not completed high school and has no job. She visits James daily and participates actively in his daily care.

For James, early intervention services - which would be identified through an Individualized Family Service Plan (IFSP) — might focus on health, medical, and family needs. Initially, the hospital and community nurses would coordinate services and plan for James's discharge. They might refer the family to the WIC program for nutritional support and to social services for financial assistance. To reduce Tina's isolation and to help her with daily activities, a parent aide might be enlisted. Later on, Tina may wish to join with a group of other young mothers for support and to better understand how to care for James. If Tina decided to return to school, access to day care would make it easier for her to do so.





significantly higher on tests of mental ability, and experienced lower mental disability rates compared to children who received only health services. The Early Intervention Collaborative Study (Shonkoff et al., 1990) found developmental gains after one year of intervention in children with identified disabilities or who were at risk for developmental problems.

### Rosa

Rosa, a 3½-year-old child, has a seizure disorder and is exhibiting developmental delays. She is enrolled in a preschool serving children with and without disabilities. Rosa's mother has provided her daily care at home. This includes frequent trips to the local health clinic and to the regional medical center, which is 50 miles from her home, for specialized medical supervision. Her father has a good job with health insurance benefits that have covered the medical bills so far, but the travel expenses and medications are not covered. The challenge is to provide coordinated health, education, and family support services for Rosa and her family within their community.

Rosa's preschool program is designed to address her needs as identified on her Individualized Education Program (IEP). The IEP was developed by Rosa's parents, a nurse from Rosa's primary health care clinic, the school psycholgost who administered developmental tests, the speechlanguage pathologist who evaluated Rosa's communication needs, and the preschool staff. The parents provided information about Rosa's daily routine and their concerns about her development and priorities to be addressed in her program. The nurse provided information to the team about Rosa's seizure disorder, what the staff should do if she has a seizure, how to administer medications at preschool, and possible side effects they might observe. The preschool staff, the psychologist, and the speech-language pathologist provided the team with information about Rosa's developmental progress in the preschool program. The staff also provided documentation about any seizures she had at preschool and her response to medications.

Together they developed a program of comprehensive, coordinated services that support Rosa and her family. They also can refer the family to additional resources, including support groups or financial resources depending on the family's expressed needs and concerns.

# How Do Early Services Help Children and Families?

Early services are designed to help children with disabilities reach their maximum potential and become as independent and productive as possible by:

- promoting development and learning for children who receive the services;
- identifying and providing timely intervention and treatment for children with health and developmental problems or who are at risk of developing problems;
- decreasing the need for costly special programs later;
- providing support to parents at a critical time in their child's life and enhance their capacity to meet their child's needs; and
- coordinating services within the community to improve access for families and assure the best use of available resources.

Early services mean different things for different people and depend on the specific needs of the child and family. The stories of James and Rosa, presented in this paper, are examples of specific needs and of the early services that can help meet those needs. Federal legislation and related funding supports the development of state and other jurisdictional service systems to meet the health, social, and developmental service needs of young children with disabilities and their families.

#### What is IDEA?

In 1986, Congress enacted Public Law 99-457, amending the Education of the Handicapped Act (EHA), which outlined requirements for statewide early intervention systems and preschool services. Now known as the Individuals with Disabilities Education Act (IDEA), the law includes the following programs that target young children, birth through 5 years of age, with special needs.

### The Program for Infants and Toddlers With Disabilities (Part H)

Part H of IDEA requires participating states and jurisdictions to plan, develop, and implement a family-centered, coordinated interagency system of early intervention services for all eligible infants and toddlers (birth through 2 years of age) with



disabilities and their families. Children are eligible for services who (a) have certain conditions which have a high probability of resulting in developmental delay (such as Down syndrome, cerebral palsy, spina bifida, hearing or vision loss), or (b) meet the state's definition of developmental delay in cognitive, physical, communication, social and emotional, or adaptive development. States also may elect to serve children at risk for developmental delay as defined by the state; currently, approximately 20% of the states and jurisdictions include these children in their eligibility definition. Family income is not a factor in determining eligibility for Part H services.

Early intervention under Part H begins with identification and referral of a child for a comprehensive multidisciplinary evaluation to determine eligibility and to recommend services. The multidisciplinary emphasis of IDEA provides many opportunities for health professionals to participate in the early intervention system, especially in identification, referral, and evaluation.

IDEA emphasizes and protects the family's role in its child's program. The evaluation team and the family together decide what combination of services will best meet the family's needs based on the family's resources, concerns, and priorities. These services and resources are listed on an Individualized Family Service Plan (IFSP). Ongoing assessment procedures monitor the child's development and the family's changing needs. Procedural safeguards protect each family's rights within the service system, including confidentiality, consent, access to records, and complaint resolution.

Every family has an identified service coordinator who helps the family access and coordinate services within the local early intervention system. This system is set up so that all agencies can work together to provide children with disabilities and their families with needed services within their communities. Early intervention services specified in IDEA may include, but are not limited to, those listed in Table 1.

Child identification, evaluation for eligibility, ongoing assessment, service coordination, IFSP development, and procedural safeguards are provided at no cost to families. Other services may be financed in a variety of ways, including sliding fees, third-party payment, or local, state, and federal funds.

### The Preschool Grants Program (Part B, Section 619)

Section 619 of Part B of IDEA mandates that state departments of education must provide, through local programs, a free appropriate public education with related services to all eligible 3- through 5-year-old children with disabilities. Referral to these programs frequently occurs through a transition process from the infant and toddlers program (Part H), or referral can be made directly to the education system by parents, health care providers, and others. Services for preschool children are determined through a multidisciplinary evaluation process and are listed on the child's Individualized Education Program (IEP). They may be provided in a variety of community preschool settings, such as day care, Head Start, and private preschools with the goal of providing services in

### Table 1 Services Provided Under IDEA

Under Part H (Birth Through 2 Years)

Assistive Technology Devices and Services Audiology Training, Family Counseling, and Home Visits Health Services Medical Services for Diagnosis or Evalua-Nursing Services Nutrition Services Occupational Therapy Physical Therapy Psychological Services Service Coordination Services Social Work Services Special Instruction Speech-Language Pathology Transportation and Related Costs

(For Part H, see 34 Code of Federal Register (CFR) §303.12(d).)

Vision Services

Under Part B
(3 Through 5 Years)

Assistive Technology Devices and Services Audiology Counseling Services Early Identification and Assessment Medical Services for Diagnosis or Evalua-Occupational Therapy Parent Counseling and Training Physical Therapy Psychological Services Recreation Rehabilitation Counseling Services School Health Services Social Work Services in Schools Special Education Speech Pathology Transportation

(For Part B, see 34 CFR §§300.5, 300.6, 300.16, and 300.17.)

settings that include children with and without disabilities to the greatest extent possible. Services are provided to enable children to benefit from educational programming in these inclusive environments. Ongoing assessment that monitors the child's progress and evolving needs is part of the IEP process. Procedural safeguards protect family rights throughout this process. Services under Part B may include, but are not limited to, those listed in Table 1.

# Where Can You Get More Information?

More information on early intervention and preschoolservices is available from a variety of health and educational professional organizations, national disability organizations, and parent organizations. For information about contacting these groups, please call the National Information Center for Children and Youth with Disabilities (NICHCY), P.O. Box 1492, Washington, DC 20013; (800) 695-0285 (Voice/TDD).

#### References

The Individuals with Disabilities Education Act, P.L. No. 101-476, 104 Stat. 1103 (1990) (codified as amended at 20 U.S.C. Secs. 1400-1485).

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This is one of a series of papers that discusses the individual components of IDEA and how health services can be fully integrated with early interven-

tion and preschool systems. Each paper is designed as a brief overview that presents practical strategies and examples of successful implementation of those strategies by agencies, organizations, and projects.

The series is written for early intervention and health care personnel from all disciplines who are working at the state and community levels. It is being distributed to the Part H Coordinator, the Section 619 Coordinator, and the ICC Chair in each state and jurisdiction. It is our hope that they will duplicate and disseminate the papers to local early intervention service programs, state and local health departments, hospitals, state and local ICCs, parent organizations, professional organizations, institutions of higher education, advocacy groups, legislators, and other relevant groups.

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